



STATE SENATOR

RICH ZIPPERER

TESTIMONY OF SENATOR RICH ZIPPERER IN SUPPORT OF SENATE BILL 210

Though small in number, some children in Wisconsin are born each year with food allergies or gastrointestinal conditions that make it difficult or impossible to consume traditional food products. These children are forced to use amino acid-based elemental formulas to provide their nutritional needs. Though these formulas are truly a wonder of science that allow these kids to grow and play along with their friends, their costs are far above what most families pay to feed their children. For many low income families, WIC helps to meet the cost demands, but for middle class families the burden can be severe. That is why I have introduced this legislation to simply allow families in this situation to keep more of what they earn and use it to provide these needed formulas to their children. This bill would establish a 50% tax credit, up to a total of \$5000 for each dependent, for families to put toward the purchase of amino acid based formulas.

Along with me today is the real driving force behind this bill, Ms. Melody McCabe. Melody is a constituent of mine, and first brought this issue to my attention by telling me about the story of her son Andrew. At this time, I would like to turn the floor over to her and at the conclusion of her comments, I would be happy to take any questions from committee members.

My son is 3 years old. He has a tube in his stomach. He is allergic to food and until recently he threw up at least once every day for 5 months. He has a rare auto-immune disorder in which his body sees food as poison. He has Eosinophilic Esophagitis Gastroenteritis. There is no cure. He will not grow out of this. The only thing keeping him alive is an amino-acid based elemental formula.

Can you imagine not being able to eat for fear of throwing up, cramping, and discomfort? Can you imagine watching other people eat while you have to be tube fed via a stomach tube with an elemental formula that will keep you alive? Me either, but I see it through my son's eyes and it's very sad.

We must go through the process of trialing different foods. One at a time for 12 weeks and to get a result, he must be put under and have an endoscopy. If he is clear, we move on to the next food. If not, we must wait for his body to be clear of white blood cells, for they are where they are not supposed to be. In order to do this, we must wait 6 weeks before trialing again.

This is all for our son to stay alive. In the meantime, we must concern ourselves with how we are to afford this elemental formula amid all the medical finances of this process. He is only 3 years old and it already costs \$6200 a year to feed him. About \$17 a day. Please consider passing this bill. For our family and for many of the other families of Wisconsin I am speaking for today. We are hard working families just trying to keep our children alive elemental formula.

Melody McCabe
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My son, Ryan, had troubles between his 6 & 9-month appointments... he gained no weight, began vomiting & had severe eczema on his cheeks, to the point of blistering. The Dr. thought he had Celiac Disease and we were sent to Children's Hospital in Milwaukee (we live in Kenosha). They ran blood work and performed an endoscopy on him. He was officially diagnosed with EE in June, 2008 at 1 year old. We removed the foods that came back as allergens on the blood test; eggs, wheat, soy, rice, nuts, oats. We also discovered he was allergic to peas. The symptoms went away. We didn't do anything for a year because he had no symptoms. Later, upon reading more information about the disease, we decided to take him back to a specialist in the GI field. She did another endoscopy on him. We then decided to go to another Dr.- an EE specialist at Children's Hospital. This Dr. removed dairy from his diet for 3 months. Because he had so many foods removed from his diet already & removing the dairy from his diet, the Dr. prescribed a formula specifically designed for GI tract problems- EleCare. My insurance carrier doesn't cover the cost of the supplement & we had to pay \$200 up front for this medication, despite paying insurance premiums. Luckily, he could still eat some foods & the supplement lasted us a month. He then had another endoscopy & nothing had changed in the esophagus, it was still inflamed. Ryan has been to the allergist & had allergy tests run as well, plus the medication to keep his disease under control. We will be going for endoscopy number 5 at the end of March. Up to this point, we have spent at least \$10,000 on this disease. This is our first child and this cost doesn't include all of the normal costs of having a child, such as day care, clothing, food, medication, normal Dr. appointments, etc. We are not frivolous people; we own a home, are not big shoppers, have been married for 7 years and are both hard-working people. We've had insurance through each of the steps in this process, but this is an expensive disease. Endoscopies are the only course of action to find out where the disease is at and there's food needed, whether it's the formula or special food because the body can't tolerate some foods. Unfortunately, in this state, the formula is not required to be covered by the insurance companies. It would be a tremendous help if this bill were passed. We aren't looking for a hand-out, but some help with a disease none of us expected to be dealing with. Thank you for your time.

Sincerely,

Janet M. Lafferty

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To Whom It May Concern!

We need Andrews Bill to be passed ! We need a tax credit for people who have family members affected by Eosinophilic Esophagitis. My family is spending \$500 every two weeks on a special formula that we make, the only food my daughter can tolerate. Insurance does not cover the formula or her Prevacid, which is a over the counter medicine that she needs to take daily. I cannot work because I have to always take my daughter to doctors appointments and to hospitals for endoscopies or feeding tube placements or other issues that arise from her having Eosinophilic Esophagitis. In addition we have to pay for her physical, occupational, and speech therapy, which insurance only pays for a small percentage of. This year alone we spent \$65,000 in expenses to take care of my daughter's Eosinophilic Esophagitis. I am not the only family who is experiencing this, as many of my friends who have kids who have Eosinophilic Esophagitis are in the same dilemma. Some of their kids are incredibly small looking for their age because they cannot afford formula that their kids need and which insurance does not cover and many of my friend's have been let go from their jobs, because their employers are fed up with them having to leave work to take care of their children who suffer with Eosinophilic Esophagitis.

Thank you for your consideration!

Renee Glassman

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